

# Unintentional asphyxia, SIDS, and medically explained deaths: A descriptive study of outcomes of child death review (CDR) investigations following sudden unexpected death in infancy

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1 **Title**

2 Unintentional asphyxia, SIDS, and medically-explained deaths: a descriptive study of outcomes of  
3 Child Death Review (CDR) investigations following sudden unexpected death in infancy.

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21

## 22 **Abstract**

### 23 **Background**

24 A comprehensive Child Death Review (CDR) programme was introduced in England in 2008 but as  
25 yet data have only been analysed at a local level, limiting the learning from deaths. The aim of this  
26 study is to describe the profile of causes and risk factors for Sudden Unexpected Death in Infancy  
27 (SUDI) as determined by the new CDR programme.

### 28 **Methods**

29 This was a descriptive outcome study using data from Child Death Overview Panel (CDOP) Form C for  
30 SUDI cases dying during 2010-2 in the West Midlands region of England. The main outcome  
31 measures were: cause of death, risk factors and potential preventability of death, and determination  
32 of deaths probably due to unintentional asphyxia.

### 33 **Results**

34 Data were obtained for 65/70 (93%) SUDI cases. 20/65 (31%) deaths were initially categorised as due  
35 to medical causes; 21/65 (32%) as SIDS, and 24/65 (37%) as undetermined. Reanalysis suggested  
36 that 9 deaths were probably due to unintentional asphyxia, with 6 of these involving co-sleeping and  
37 excessive parental alcohol consumption. Deaths classified as 'undetermined' had significantly higher  
38 total family and environmental risk factor scores (mean 2.6, 95% CI 2.0– 3.3) compared to those  
39 classified as SIDS (mean 1.6, 95% CI 1.2-1.9), or medical causes for death (mean 1.1, 95% CI 0.8-1.3).  
40 9/20 (47%) of medical deaths, 19/21 (90%) SIDS and 23/24 (96%) undetermined deaths were  
41 considered to be potentially preventable. There were inadequacies in medical provision identified in  
42 5/20 (25%) of medically explained deaths.

### 43 **Conclusions**

44 The CDR process results in detailed information about risk factors for SUDI cases but failed to  
45 recognise deaths probably due to unintentional asphyxia. Many SUDI occurred in families with

46 mental illness, substance misuse and chaotic lifestyles and most in unsafe sleep-environments. This  
47 knowledge could be used to better target safe sleep advice for vulnerable families and prevent SUDI  
48 in the future.

## 49 **Key Words**

50 Sudden Unexpected Death in Infancy (SUDI)

51 Sudden Infant Death Syndrome (SIDS)

52 Child Death Review (CDR)

53 Unintentional Asphyxia

54 Risk factors

55

## 56 **Key points**

57 The CDR process provides valuable information on the profile of causes and risk factors for SUDI but  
58 is currently not recognising deaths from accidental asphyxia.

59 Most SUDI still occur in hazardous sleep environments despite public health campaigns.

60 Poor parenting, particularly the combination of excess parental alcohol consumption and co-  
61 sleeping, was a factor in many unexplained SUDI deaths.

62 Research is needed to help target safe-sleep information better at high risk families.

63 Difficulties with health care service provision may have contributed to some medically explained  
64 deaths.

65

## 66 **BACKGROUND**

67 Since 2008, all child deaths in England are subject to local child death review (CDR) with the aim of  
68 improving the welfare and safety of all children in the locality [1]. As yet data from this process have  
69 only been analysed at a local level limiting any wider learning. As part of a broader evaluation of the  
70 multi-agency investigation of Sudden Unexpected Death in Infancy (SUDI) we analysed CDR data on  
71 all SUDI cases in the West Midlands region of England from 2010-12 with the aim of improving our  
72 understanding of causes and risk factors for deaths to help prevent future deaths.

73 All unexpected child deaths, including SUDI cases, have mandatory detailed multi-agency  
74 investigation by police, health and social services aiming to identify, as far as possible, the complete  
75 cause of death including any relevant risk factors. This information is then anonymised and reviewed  
76 by local multi-agency Child Death Overview Panels (CDOP); cases are discussed and a standard  
77 template (the CDOP Form C) is completed for each child, summarising the case and detailing cause  
78 and risk factors for death. These risk factors include those intrinsic to the child, in the family or  
79 environment, parenting capacity, and service provision. Risk factors can be marked on the Form C as  
80 yes/no, graded 0-3 for relevance or be described in free text. Panel members also determine  
81 whether the death is considered preventable; this is defined in the CDR statutory guidance as 'those  
82 in which modifiable factors may have contributed to the death. These are factors defined as those,  
83 where, if actions could be taken through national or local interventions, the risk of future child  
84 deaths could be reduced.' [1]

85 SUDI is defined as 'the death of an infant that was not anticipated as a significant possibility 24  
86 hours before the death, or where there was a similarly unexpected collapse leading to the death'[2].  
87 SUDI cases may have a full cause for the death determined but most remain unexplained and are  
88 labelled as either undetermined or Sudden Infant Death Syndrome (SIDS)[3]. Risk factors for SIDS  
89 are well known including parental smoking [4], hazardous sleeping environments[5] and prone sleep  
90 position [6]. Some SUDI are caused by unintentional asphyxia such as overlaying by a parent; these  
91 deaths are difficult to determine as SIDS deaths and those from unintentional asphyxia have many  
92 features in common [7], differentiation relies on parental accounts and scene examinations because  
93 post-mortem examination findings are often insignificant [8] and not diagnostic [9].

94 We undertook a descriptive study of CDR outcomes for SUDI cases based in the West Midlands; this  
95 area has an infant mortality rate of 5.3 per 1000 live births [10] which is one of the highest in  
96 England.

97 The research question was: What is the profile of causes and risk factors for SUDI in one region of  
98 the UK?

99

## 100 **METHODS**

101 We obtained the dates of birth and death of all SUDI cases in the study region aged between one  
102 week and one year, dying between 1 September 2010 and 31 August 2012, from the pathology  
103 departments at Birmingham Women’s Hospital and Birmingham Children’s Hospital. These two  
104 centres conduct all infant post-mortem examinations for the locality. The study region consisted of  
105 the counties of Warwickshire, West Midlands, Worcestershire, Staffordshire, Shropshire and  
106 Herefordshire. We contacted the Chairs of all ten local CDOPs and asked for copies of the Form C for  
107 all relevant SUDI cases. These forms were completed and provided to us in an anonymised format.

108 There was considerable variation in how Form Cs were completed by individual CDOPs leading to  
109 difficulties comparing forms. The grading of risk factors using the 0-3 scale was inconsistent; risk  
110 factors were frequently only mentioned in the narratives but the relevance of these was not always  
111 recognised, leading to disparate conclusions on the potential preventability of deaths. Therefore,  
112 using the data available on each Form C, JG and CE, who are experienced CDOP members,  
113 independently completed the risk factor yes/no and 0-3 grade fields and considered the potential  
114 preventability of each death. We then compared results and discussed and resolved any differences.  
115 To assist coding, we created a reference list of risk factors for SUDI based on the Avon Clinico-  
116 Pathological Classification [11]; these risk factors are shown in table 1.

117

118 There is no published guidance on determining risk factors for parenting capacity or service  
119 provision. We considered parenting capacity as a risk if poor parenting had contributed in any way to  
120 the death, even if an isolated event; this included co-sleeping deaths with parents consuming more

121 than two units of alcohol but excluded other unsafe sleep deaths without substance involvement.  
122 Risk factors for service provision included failings in medical care, lack of provision of services or  
123 access to them. We decided that parents not engaging with services, for whatever reason, were  
124 parenting issues rather than service provision issues, although we recognised that in some cases lack  
125 of engagement may reflect lack of provision of services appropriate to the needs of vulnerable  
126 families.

127 We entered the following data items for each case into a SPSS database: age at death, narrative  
128 description of cause of death, presence of significant risk factors at level 2 or greater, potential  
129 preventability of death, and documented provision of safe sleep information. We created a total  
130 family and environmental risk factor score for each case. We gave a score of 1 for each of: any  
131 unsafe sleeping environment (such as the use of soft bedding or co-sleeping); parental alcohol  
132 consumption of greater than two units or illicit drug use the night before death; parental mental  
133 illness at the time of death; housing issues; domestic violence; and maternal smoking. The maximum  
134 score was 6; this score was intended as a descriptive tool detailing the circumstances of deaths  
135 rather than as an assessment of effectiveness of determining risk factors.

136 We considered the possibility of unintentional asphyxia for all unexplained deaths; this was  
137 considered separately from the total family and environmental risk factor score. Asphyxia was  
138 considered probable if both the autopsy findings and the circumstances of death supported this, if  
139 the infant was found under a parent or at the bottom of the parents' bed under bedding, or if there  
140 were other significant suffocation hazards. Infants found face down were not considered to have  
141 asphyxiated in the absence of other factors as this is a common SIDS finding, possibly representing a  
142 failure of arousal mechanisms [12]. This method may both overestimate or underestimate  
143 unintentional asphyxia, recognising that overlaying may occur after the infant has died of another  
144 cause, or that a parent may cause asphyxia through overlaying, but subsequently move so the infant  
145 is found with no apparent airway obstruction.

146 We used 3-way chi-squared test for determining significant associations between risk factors and  
147 categories of death and for acute illness which was not applicable as a risk factor for medically  
148 explained deaths, a 2-way chi-squared test was performed comparing SIDS with deaths classified as  
149 undetermined, with  $p < 0.05$  considered statistically significant.

150 Ethical approval was granted from the University of Warwick Biomedical and Scientific Research  
151 Ethics Committee.

## 152 **RESULTS**

153 There were 70 SUDI cases having post-mortem examinations at the two pathology departments  
154 during the two year study period with the Form C available for 65 cases (93%). Due to the  
155 anonymisation of the forms we could not ascertain which cases were missing or the reasons for non-  
156 availability. Form Cs had complete information (although not necessarily correctly formatted) in  
157 53/65 (82%) cases. In 10/12 cases missing information related to a single item. Two cases, from  
158 different CDOPs, were missing several items of information in one of which it was not possible to  
159 determine the preventability of death.

160 In 52/65 (80%) cases there was complete agreement initially between CE and JG on reanalysis of  
161 Form Cs. In 30/65 (46%) cases reanalysis of Form Cs only involved standardising the format of  
162 information but in 35/65 (54%) cases reanalysis included reinterpreting the information according to  
163 our reference list, leading to reclassification of risk factors and potential preventability of death.

164 The median age at death was 2.3 months for all deaths, 3.1 months for medical deaths, 2.0 months  
165 for SIDS, and 2.1 months for undetermined deaths. 48/65 (74%) deaths were of males.

### 166 **Causes of death**

167 Causes of death are shown in table 2.

168 Most deaths (69%) remained unexplained. 12/20 medical deaths were from infection and 6/20 from  
169 cardiac disease.



170 **Deaths due to unintentional asphyxia**

171 No deaths were identified on Form Cs by CDOPs as due to unintentional asphyxia; however after  
172 reanalysis 2/21 SIDS and 7/24 undetermined deaths were considered probably asphyxial. In two  
173 cases there were significant post-mortem examination findings consistent with asphyxia. Five  
174 infants were found at the bottom of their parents' beds, face down and entirely covered with  
175 bedding, two infants were found directly under parents. In six of the nine cases, parents were  
176 probably intoxicated with alcohol, all six deaths involved co-sleeping and one infant was found under  
177 a parent. The remaining 17 undetermined deaths met criteria for a diagnosis of SIDS [3] and were  
178 recategorised as such.

179 **Risk Factors**

180 The distribution of risk factors in relation to the CDOP classification of cause of death is shown in  
181 figure 1. Risk factors and potential preventability of death are shown in table 3.

182

183 **Risk Factors Intrinsic to the Child**

184 The acute illness directly causing death was the only intrinsic risk factor in 9/20 medical deaths.  
185 There were no significant differences between category of death and previous prematurity or  
186 congenital anomalies; this probably reflects that infants with congenital anomalies or previous  
187 prematurity have increased vulnerability so are more likely than other infants to die of any cause.

188 **Risk Factors in the Family and Environment**

189 The total number of family and environmental risk factors and cause of death are shown in figure 2.  
190 Those deaths classified by CDOPs as undetermined had significantly higher total family and  
191 environmental risk factor scores with a mean of 2.6 (95% CI 2.0– 3.3) compared to 1.6 (95% CI 1.2-  
192 1.9) for SIDS and 1.1 (95% CI 0.8-1.3) for medical causes. SIDS and undetermined deaths were  
193 significantly more likely to be in an unsafe sleep environment than medically-explained deaths and  
194 to occur in families with maternal smoking in pregnancy or postnatally (p=0.006). The parents of

195 undetermined cases were significantly more likely than those of SIDS or medically-explained deaths  
196 to have consumed more than two units of alcohol or taken illicit drugs the night before death  
197 ( $p=0.004$ ), or to have mental health problems ( $p=0.009$ ). The combination of alcohol consumption  
198 and co-sleeping occurred in 2/8 co-sleeping SIDS and 6/14 co-sleeping undetermined deaths. In  
199 three unexplained deaths co-sleeping occurred without other environmental risk factors; two cases  
200 were of premature infants who had barely reached term; only one infant died co-sleeping in the  
201 absence of any other risk factors.

202 Only three unexplained deaths had no risk factors in the family and environment; however all of  
203 these infants were intrinsically vulnerable due to previous prematurity, multiple births or congenital  
204 abnormalities.

#### 205 **Risk Factors for Parenting Capacity**

206 Risk factors for parenting capacity were identified by local CDOPs in 9 cases and by the research  
207 team in an additional 12 cases; the risk factors identified by both groups were similar. Risk factors  
208 for parenting capacity were significantly associated with undetermined deaths ( $p=0.016$ ); mainly due  
209 to co-sleeping with alcohol consumption. Poor parenting in some families had been a concern to  
210 professionals prior to the death. Parenting risk factors for medical deaths involved young mothers  
211 with chaotic lifestyles failing to recognise illness in their infants or not engaging with services. There  
212 were no deaths in this series for which the CDOP had identified child maltreatment or intentional  
213 asphyxiation as a cause.

#### 214 **Risk Factors for Service Provision**

215 There were five medically-explained deaths in which issues with service provision potentially  
216 contributed. In two cases infants missed immunisations and died of vaccine preventable diseases;  
217 primary care services had not engaged with parents about this. In three cases there was concern  
218 that primary care or community health teams had not managed cases appropriately.

219 **Potential Preventability of deaths**

220 Potential preventability of death was significantly associated with SIDS and undetermined deaths  
221 ( $p=0.001$ ) although nearly half of medical deaths were also potentially preventable.

222 **Provision of safe sleep information**

223 In 22/45 unexplained deaths it was clearly documented that parents had been given safe sleep  
224 information but in two of these language difficulties may have limited its value. In 5/23 cases  
225 without documented information provision families had not engaged with services so may not have  
226 received safe sleep advice.

227 **DISCUSSION**

228 Very few SIDS or undetermined infant deaths occurred in the absence of environmental risk factors,  
229 and these few concerned inherently vulnerable infants. One-fifth of otherwise unexplained SUDI  
230 were probably caused by unintentional asphyxia; in these cases commonly parents co-slept with  
231 infants after excessive alcohol consumption. Those deaths probably caused by unintentional  
232 asphyxia, along with a majority of those that remained unexplained may have been preventable had  
233 parental care been different, particularly if safe sleeping advice had been consistently followed,  
234 including avoiding co-sleeping if parents have consumed alcohol or are smokers or the infant is  
235 premature. A minority of medically-explained deaths may have been preventable had different  
236 actions been taken by health care providers.

237 This is the first study to combine data from several regional CDOPs enabling a large set of similar  
238 deaths to be studied; although CDOPs were established in 2008, as yet no national outcomes have  
239 been published. Although the results are purely from the West Midlands region of England, the  
240 findings should be generalizable as the profile of risk factors and causes of death is similar to those  
241 found in other UK or international studies [13] [14]. Detailed information on risk factors was  
242 available for all SUDI cases regardless of final cause of death as all SUDI cases had complete multi-  
243 agency investigations. A limitation of the study is that the quality of the data was entirely dependent

244 on individual CDOPs; there were significant disparities of the detail recorded on Form Cs. Potentially,  
245 some information on risk factors collected for medically-explained deaths was subsequently not  
246 recorded on Form Cs, no longer being deemed relevant; however this seems unlikely as most Form  
247 Cs, regardless of cause of death were very detailed. Our interpretation that lack of engagement by  
248 parents with services was a parenting risk factor rather than that of service provision may have  
249 resulted in an underestimation of the service provision concerns as these were only identified in  
250 medically-explained deaths. Other research has found service provision and in particular lack of  
251 recognition of illness to be relevant in all types of SUDI [2]. It could be that the lack of engagement  
252 may reflect services that are poorly suited to the needs of vulnerable families and thus be a service  
253 provision issue rather than poor parenting as such. However, in some cases service providers had  
254 documented repeated attempts to engage with parents but in many others we had little information  
255 to inform our judgement. Another criticism of our analysis could be that we were unduly harsh in  
256 our consideration of risk factors for parenting capacity. However, our interpretation of the  
257 combination of alcohol and co-sleeping as a parenting risk concurs with a study of CDR panel  
258 members from the USA where 89% of respondents agreed that neglect played a role in such deaths  
259 [15].

260 This is the first study to evaluate the English multi-agency SUDI investigations in routine practice.  
261 Only one other study has used a multi-agency approach to investigating SUDI but the clinicians were  
262 assisted by dedicated research teams [16]; despite this there were similar proportions of medically-  
263 explained deaths, rates of maternal smoking and hazardous sleeping environments[13]. Other  
264 studies of outcomes of SUDI investigations found that missing information from death scenes or  
265 concerning parental alcohol and smoking habits were commonplace[14, 17, 18]; in comparison only  
266 minimal information was missing in this study. This shows not only the quality of the CDOP data but  
267 also of the robustness of the multi-agency investigative process.

268 This study highlights the difficulties in correctly classifying causes of infant deaths; there were  
269 several deaths probably due to unintentional asphyxia but not labelled as such. This reflects  
270 standard UK practice as in 2014 only 6 infant deaths nationally were registered with ICD10 code W75  
271 (accidental suffocation and strangulation in bed) [19]. There is a wide variation internationally in the  
272 use of ICD10 code W75 for infant sleep related deaths, ranging from 1.1% in Germany to 31.7% in  
273 New Zealand with England and Wales at 3.8% [20]; some of this variation may be due to differences  
274 in CDR with countries such as New Zealand having a robust CDR process [21]. Additionally, in our  
275 study only around half of unexplained deaths were categorised as SIDS with the remainder,  
276 especially those with more risk factors, labelled as undetermined. All these deaths, having had the  
277 requisite investigations, could be correctly classified as SIDS [3] although this is not current UK  
278 paediatric pathologists' practice [22]. If the trend is to label more deaths as undetermined,  
279 combining SIDS and unintentional asphyxia deaths into the same category, this will impede further  
280 analysis of causes of death thus limiting possible learning and potential strategies to prevent future  
281 deaths.

282 This study has shown the utility of the new English CDR system in identifying risk factors for SUDI;  
283 this can then allow appropriate preventative strategies to be developed. This is particularly pertinent  
284 as the study clarified that most unexplained infant deaths are potentially preventable occurring in  
285 highly hazardous sleeping environments and in families with mental illness, drug or alcohol misuse  
286 and chaotic lifestyles. Clearly there are difficulties with health education messages either not  
287 reaching these families, parents possibly not understanding the information, or parents deciding not  
288 to follow safe-sleep advice [23]. Current practice in the region is that safe sleep information is  
289 shared with all families before and after birth by both midwives and health visitors; however this is  
290 usually limited to a brief discussion supported by written information [24]. When families declined  
291 to engage with health professionals it limited their opportunity to access safe sleep information.

292 This study raises two challenges: first, we need to find ways of improving the CDR process for SUDI  
293 cases, including better recognition of parenting risk factors and identification of unintentional  
294 asphyxial deaths. If we do not acknowledge these issues we cannot consider preventative strategies.  
295 Secondly, we need to consider how best to share safe-sleeping advice so that we can then find  
296 better ways to support families in making wiser choices to allow their children to grow up healthily.

## 297 **DECLARATIONS**

### 298 **List of abbreviations**

299 CDOP Child death overview panel

300 CDR Child death review

301 SIDS Sudden infant death syndrome

302 SUDI Sudden unexpected death in infancy

### 303 **Ethical approval**

304 This study was approved by the University of Warwick Biomedical and Scientific Research

305 Committee, reference number 245-10-2012

### 306 **Competing interests**

307 JG had financial support from NIHR for the submitted work; all authors had no financial relationships  
308 with any organisations that might have an interest in the submitted work in the previous three  
309 years; no other relationships or activities that could appear to have influenced the submitted work.

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316 of the NHS, the NIHR or the Department of Health.

317

318

### 319 **Authors contributions**

320 The study was designed by JG, FG and PS. JG collected all data, conducted the analyses and wrote  
321 the initial report. CE and JG reanalysed Form Cs. FG and PS advised on study progress and data  
322 analysis. All authors commented on and approved the final version of the manuscript, have a copy of  
323 the manuscript and share responsibility for the results.

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### 328 **Availability of data and materials**

329 Data may be available on request from the first author.

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417 **Table 1 Evidence base for risk factors for SUDI**

Category	Risk Factor	Reference
Intrinsic to the child	Acute illness (eg URTI /otitis media) with symptoms present at time of death but not actual cause of death	Gilbert et al. [25]
	Preterm birth before 37 weeks gestation	Blair et al. [13]
	Congenital anomaly not causing death	Leach et al. [26]
	Multiple birth	Carpenter et al. [27]
	Previous unexplained infant death	Carpenter et al. [28], Bacon et al. [29]
	Small for gestational age	Leach et al. [26]
	Male infant	Leach et al. [26]
Family and Environment	Symptomatic depression in mother or primary carer at time of death	Mitchell et al. [30]
	Alcohol use by mother > 2 units in last 24 hours	Carpenter et al. [31], Blair et al. [13]

	Substance misuse by parent	Carpenter et al. [31], Blair et al. [13]
	Smoking by mother in pregnancy or postnatally	Blair et al. [13]
	Poor housing or overcrowding	Spencer, Logan [32], Leach et al. [26]
	Domestic violence	Spencer, Logan [32]
	Co-sleeping	Carpenter et al. [31], Blair et al. [13]
	Sleeping on pillow or other soft surface eg adult duvet	Blair et al. [13]
	Sleeping prone or side sleeping	Carpenter et al. [27]

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419 **Table 2 Classification of cause of death**

Cause of death		Pathologist/Coroner classification	CDOP classification	Research team classification
Medical Cause		20 (31%)	20 (31%)	20 (31%)
Unintentional asphyxia		0 (0%)	0 (0%)	9 (14%)
Unexplained, of which:		45 (69%)	45 (69%)	36(55%)
	SIDS	19 (29%)	21 (32%)	36(55%)
	Undetermined	26 (40%)	24 (37%)	0 (0%)

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421 **Table 3 Risk factors and potential preventability of death**

	CDOP Classification			
Risk Factor	Medical cause of death (n=20*)	SIDS (n=21**)	Undetermined (n=24)	Chi-Square (p-value)
<b>Factors intrinsic to the child</b>				
Any intrinsic risk factor	Not Applicable	9 (43%)	15 (63%)	1.348 (>0.25)
Acute illness	Not Applicable	4(19%)	9 (38%)	1.605 (>0.25)
Prematurity	8 (40%)	5 (24%)	3 (13%)	4.400 (>0.25)
Congenital anomaly	6 (30%)	2 (10%)	4 (17%)	2.735 (>0.25)
<b>Factors in the family and environment</b>				
Any unsafe sleep environment	8 (40%)	15 (71%)	20 (83%)	8.431 (0.015)
Co-sleeping with a parent	5 (25%)	8 (38%)	14 (58%)	4.672 (0.097)
Parental alcohol or illicit drug use	2 (10%)	3 (14%)	12 (50%)	10.981 (0.004)
Maternal smoking	6 (30%)	11 (52%)	20 (83%)	10.246 (0.006)
Current parental mental health issues	2 (10%)	0 (0%)	8 (33%)	9.432 (0.009)
Housing Issues	4 (20%)	5 (24%)	6 (25%)	0.94 (0.954)

Domestic violence	4 (20%)	1 (5%)	4 (17%)	2.673 (0.263)
<b>Factors in parenting capacity</b>				
Parenting capacity	3/20 (15%)	5 (24%)	13 (54%)	8.276 (0.016)
<b>Potential preventability of death</b>				
Death potentially preventable	9 (47%)	19 (90%)	23 (96%)	19.574 (0.001)

422 \*for 1 medical death lack of information meant that preventability of death could not be assessed

423 \*\* for 1 SIDS case information on factors intrinsic to the child was missing

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